



THE NEXT GENERATION OF FAMILY SUPPORT SERVICES

Working Toward Sustainable Futures

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Topics

- A bit of background and history
- Next Generation of Family Support Recipients
- Challenges Faced by Policy Makers
- Facing the Challenge to build a Sustainable Future
- New Directions
- What YOU can do?



Some History ...

- Most people with developmental disabilities live at home with families (especially children).
- Prior to the mid 1970s families received little, if any support.
- Families had two choices: out of home placement or care at home with no support.
- The first state family support program was established in PA in 1972.
- Most states followed the lead in the 1980s.
- Programs primarily focused on “child centered” services and “respite,” though some – like Iowa – established “cash subsidy” programs
- The goal was primarily to deter out-of-home placement.



Where We Are...

- Family support means different things to different families.
- Family support programs make use of structured services, as well as informal or natural supports.
- Family support promotes “family empowerment” themes
- The idea is to provide “whatever it takes” for families of people with disabilities so that they can live as much like other families as possible.



Where We Are...

- Every state now indicates the presence of a family support program.
- Over 30 states have family support legislation.
- States vary greatly in program design.
- There was a great reliance on “state revenue only”.
- Family Support is experiencing great stress nationally



Things Have
and Are
Changing...



This ain't the same family support it
was ten years ago!

Things Have Changed ...

- Medicaid is increasingly in play. Help is defined as what is Medicaid reimbursable.
 - “Family Support “ is not a reimbursable service.
 - Not all children qualify.
 - Focus is on the “Medicaid beneficiary,” not “the family.”
- Increasingly we focus on adults at home, not just children.
- There is confusion about what is “family support” and what is “in home support”
- There is confusion between “self-direction” and “family direction.”

Next Generation of Family Support Recipients

Children and adults at home with families

Family members who provide support

- Parents, brothers & sisters, extended family
- Parents with disabilities
- Families of ethnic origin
- Military families
- Younger and older support-givers
- Wide geographic diversity

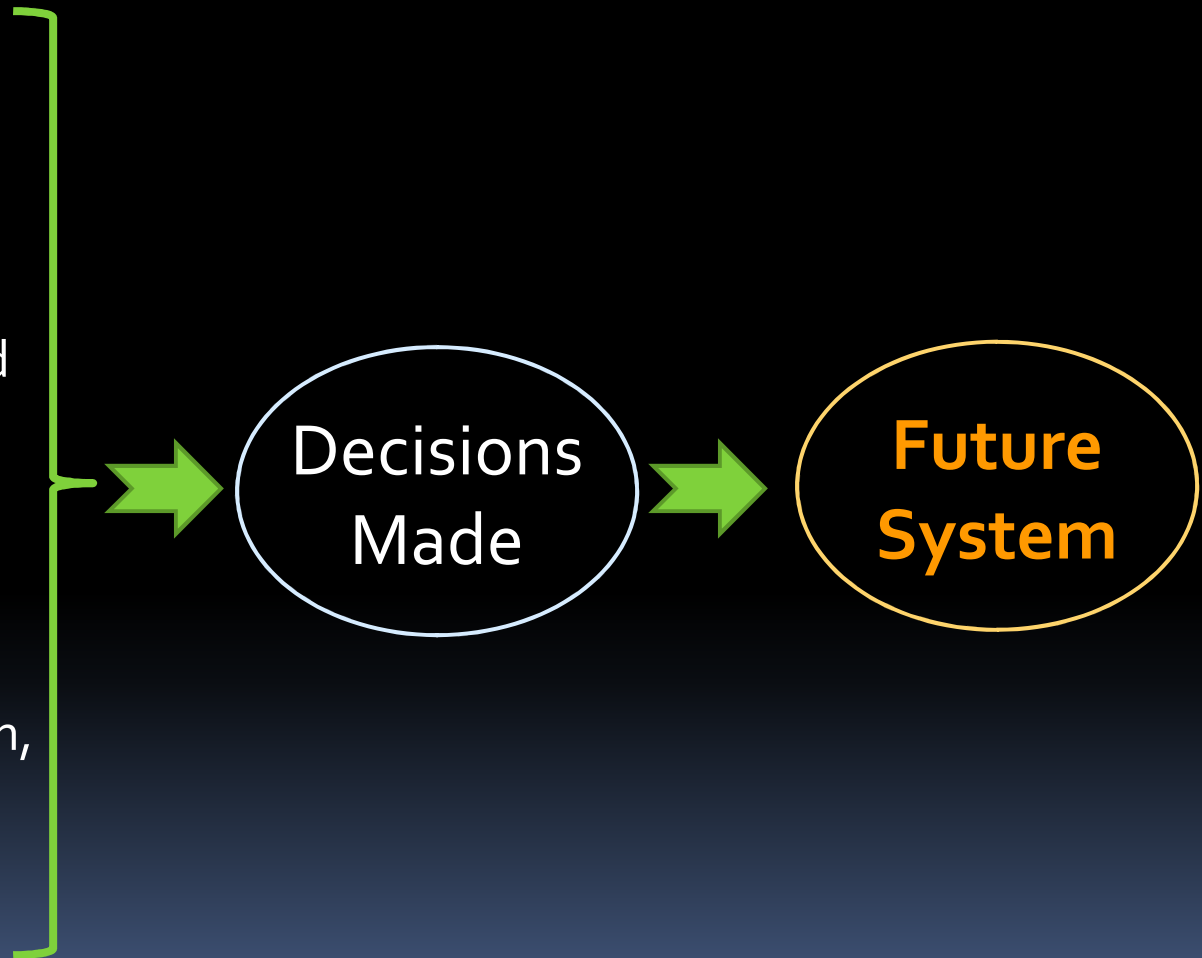
Seeking support.
Recipients have high expectations:

- Individual self-direction
- Family directed services
- Cultural competence
- Emphasis on community integration
- Flexible supports to accommodate needs over family lifespan

**Next
Generation
of Family
Support
Recipients**

Challenges Faced By Policy Makers...

- Budget stress
- Accelerating service demand
- Reliance on legacy and inefficient systems
- Workforce shortages
- Continued push for community integration, participation, contribution... self direction.

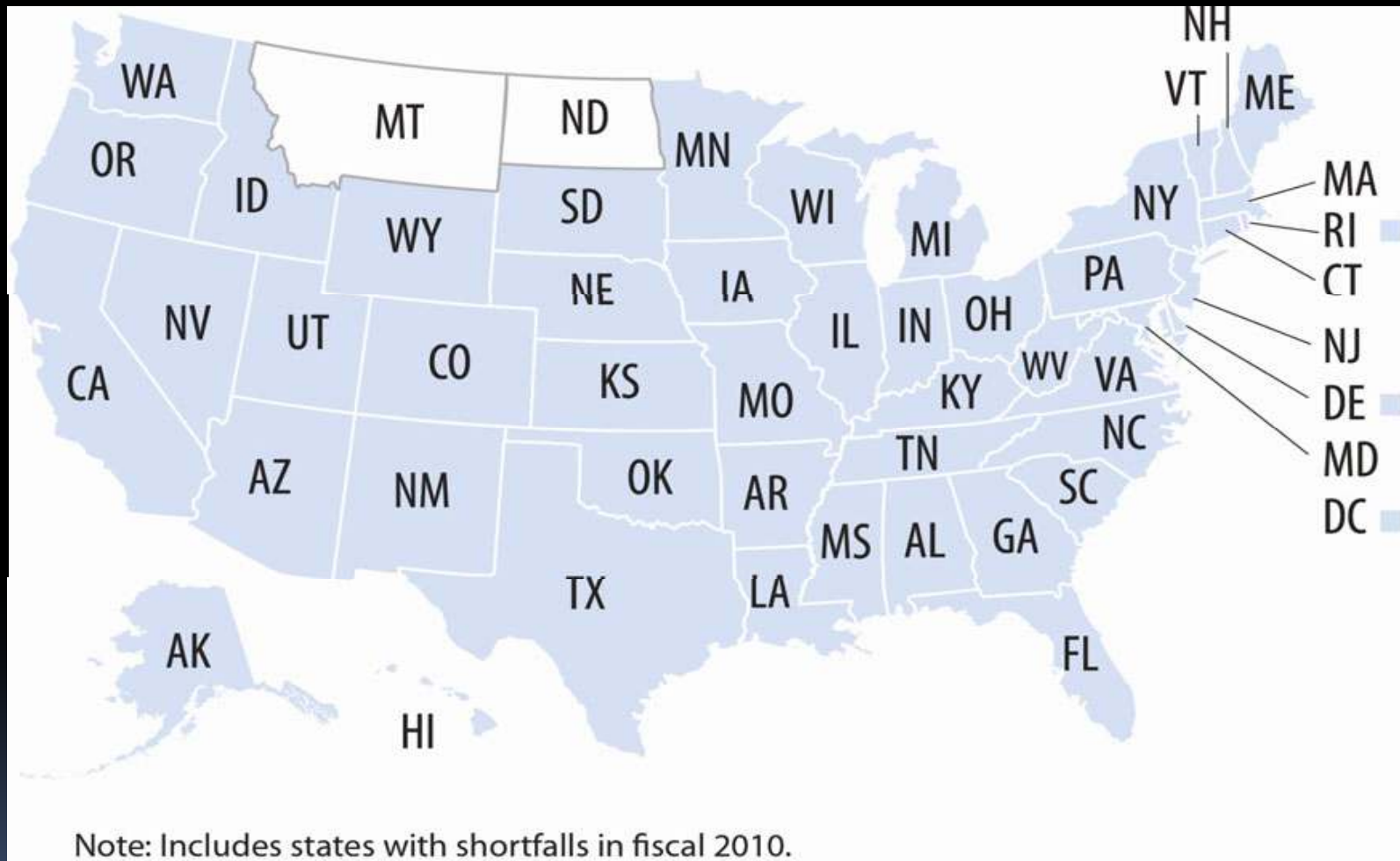


Budget Stress?

- Afghanistan war continues with Iraq still on our minds
- Unemployment rate up
- Economy falters
- States face revenue shortfalls



48 States Face Budget Shortfalls

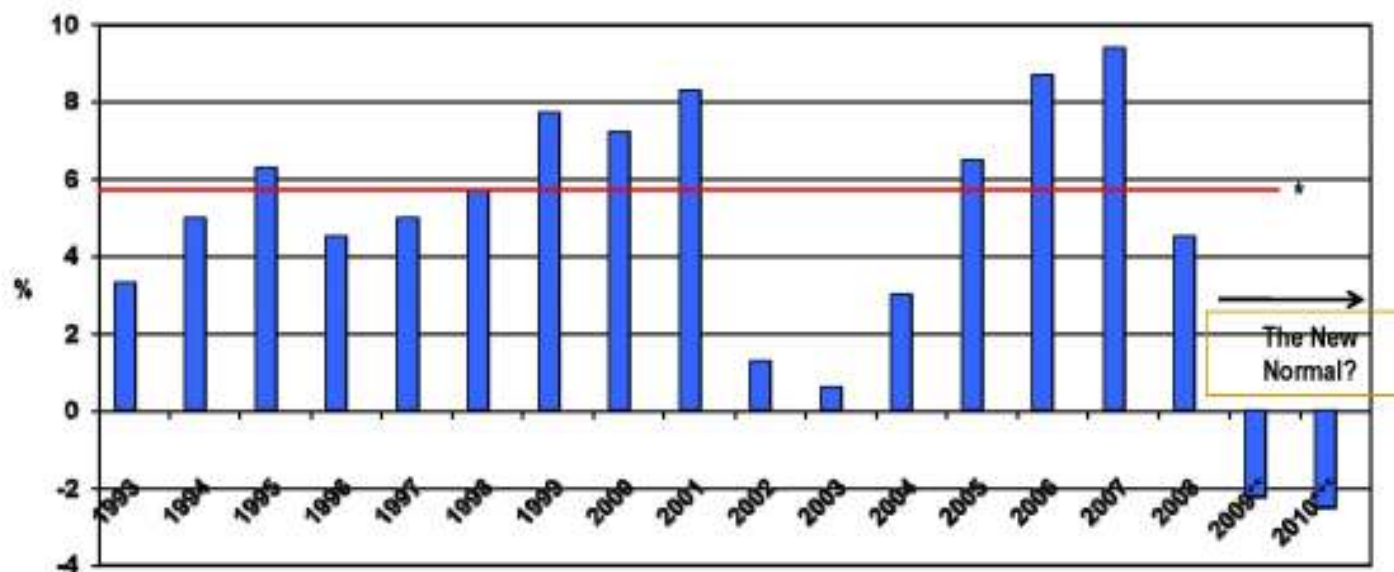


McNichol & Johnson, Center on Budget and Policy Priorities, February 2010



Negative Spending in Both FY 2009 and FY 2010

General Fund Expenditure Growth (%)



*32-year historical average rate of growth is 5.9 percent

***Fiscal 10 numbers are recommended

**Fiscal 09 numbers are estimated

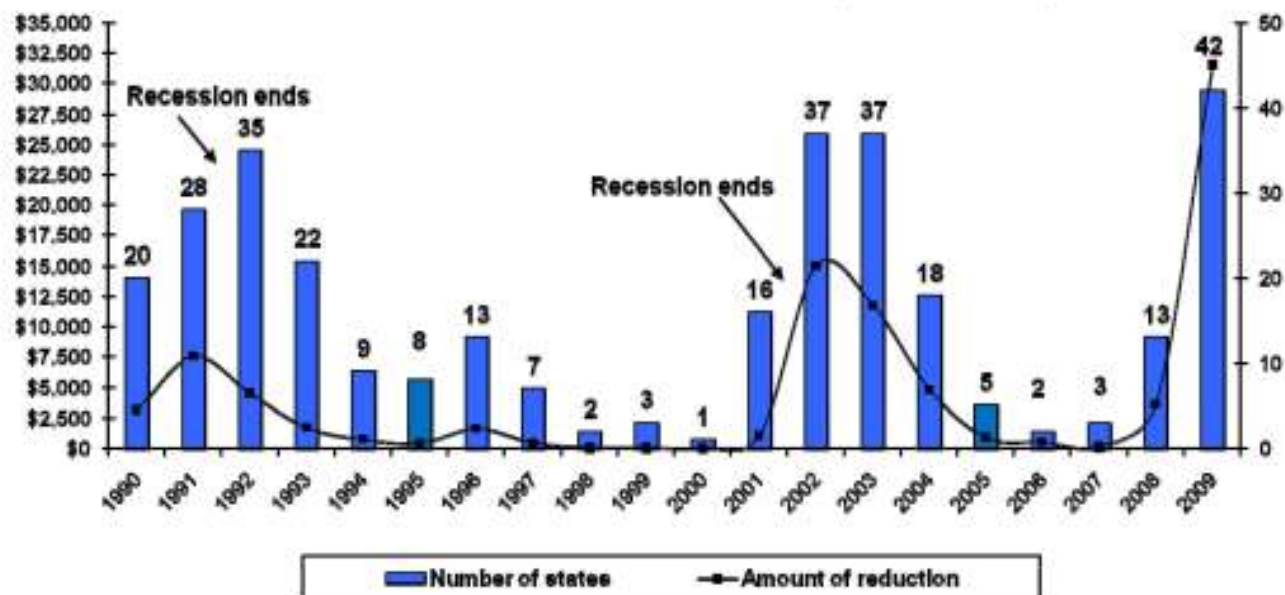
Source: NASBO June 2009 Fiscal Survey of States

NASBO



Budget Cuts at Record Levels

**Budget Cuts Made After the Budget Passed,
Fiscal 1990-Fiscal 2009 (\$ millions)**



Source: June 2009 Fiscal Survey of States

The Situation Boils Down To...

- This is the worst recession since the 1930s and has caused the steepest decline in state tax receipts on record.
- States are struggling to balance their 2010 budgets. Because revenues have fallen short of projections, mid-year shortfalls have opened up in 41 states, totaling \$38 billion or 7% of these budgets (which began July 1 in most states).
- The new shortfalls are in addition to the gaps states closed when adopting fiscal year 2010 budgets earlier this year.
- Counting both initial and mid-year shortfalls, 48 states have addressed or still face such shortfalls in their budgets for fiscal year 2010, totaling \$196 billion.
- Fiscal problems will continue into the next year and likely beyond.
- Fiscal year 2011 gaps — both those still open and those already addressed — total \$103 billion or 17 percent of budgets for the 42 states that have estimated the size of these gaps.
- When all is said and done, states will have dealt with a total budget shortfall of some \$375 billion for 2010 and 2011.

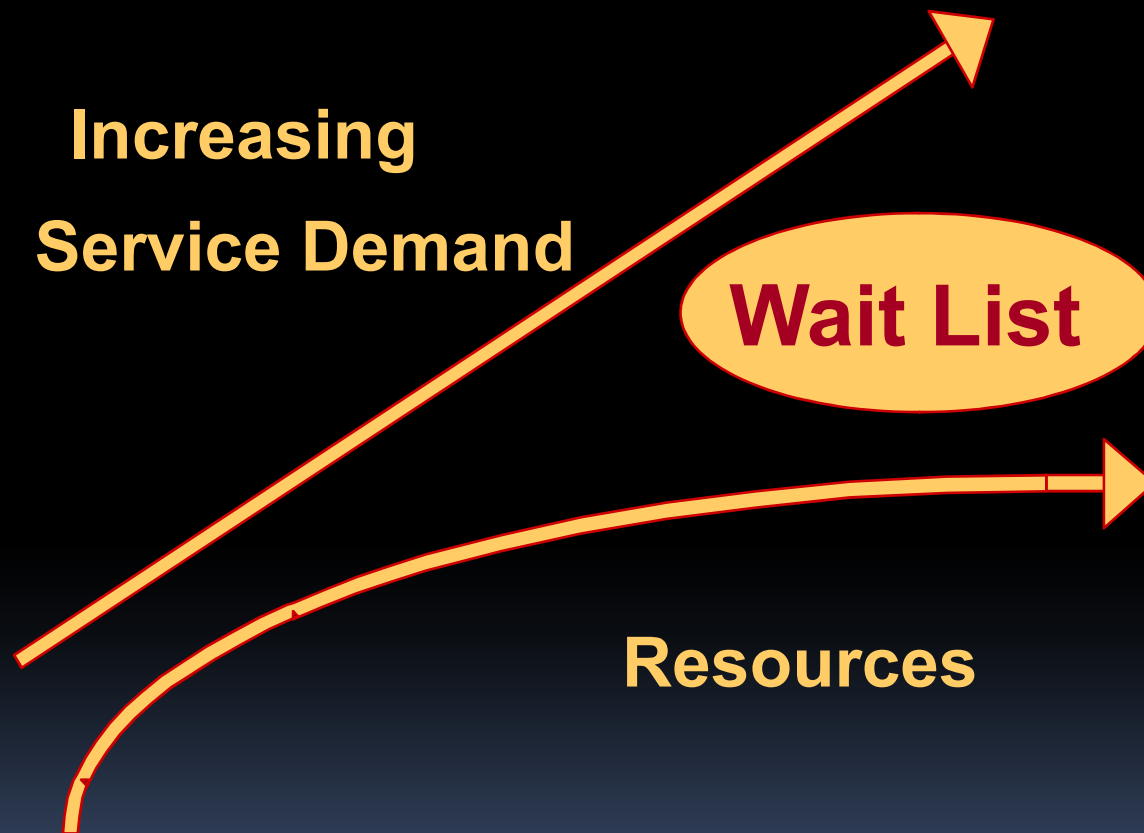
McNichol & Johnson, Center on Budget and Policy Priorities, February 2010



Service Demand Is Going Up!

- Demand for publicly-funded developmental disabilities services is growing nationwide.
- It is increasing at a rate greater than population growth alone.
- This increase in service demand is driven by:
 - People living longer ... or surviving trauma
 - Aging baby boomers
- Turnover among individuals receiving services is reduced so that there is less capacity to absorb new demand
- There is a growing number of individuals who live in households with primary caregivers who are themselves aging.

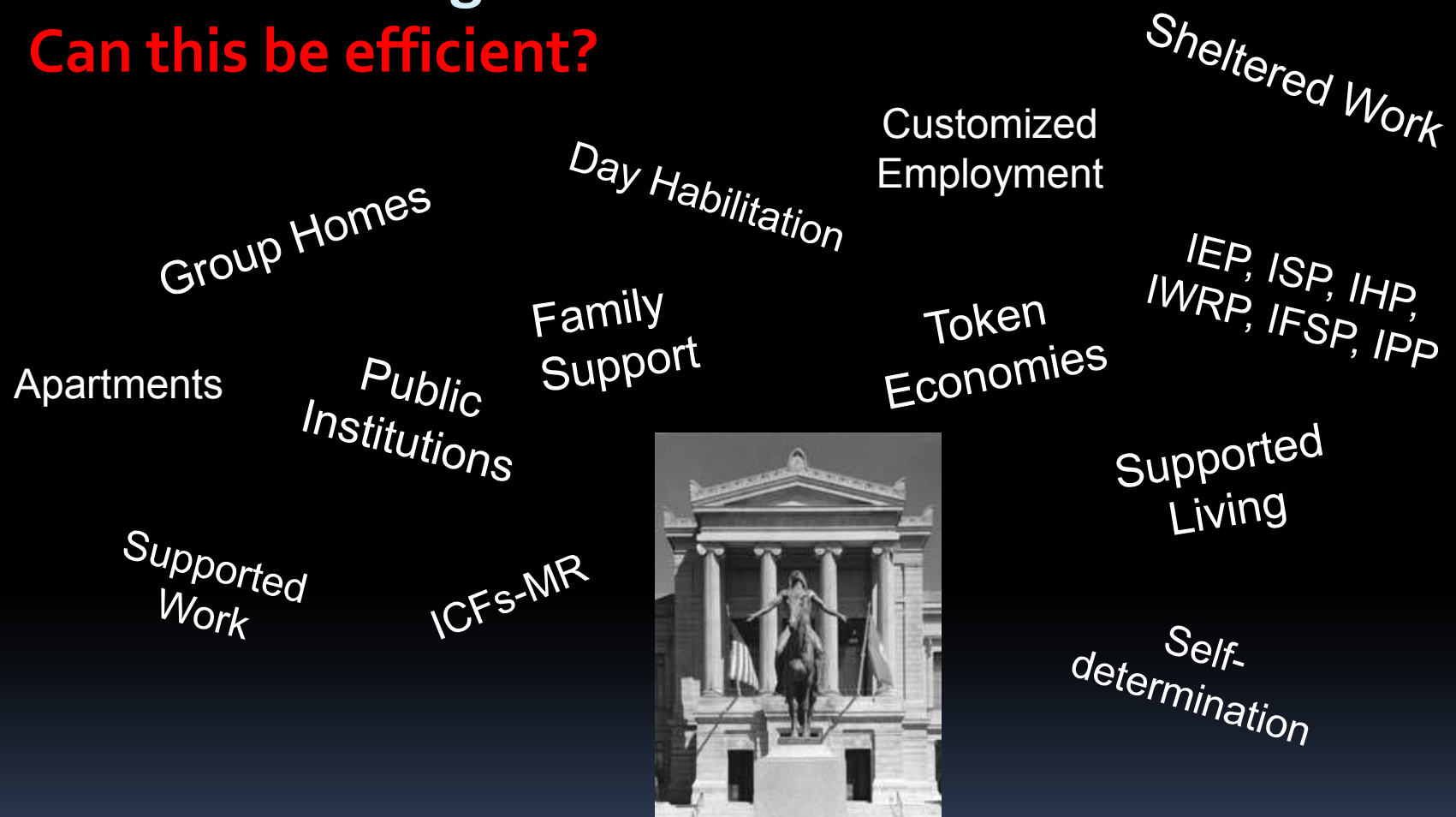
States Face a Big Problem...



Reliance on Legacy Systems...

It's A Living Museum ...

Can this be efficient?



1956... 1962... 1972 ... 1976...1983... 1987.. .1992... 1997.. 2000... 2003...2008

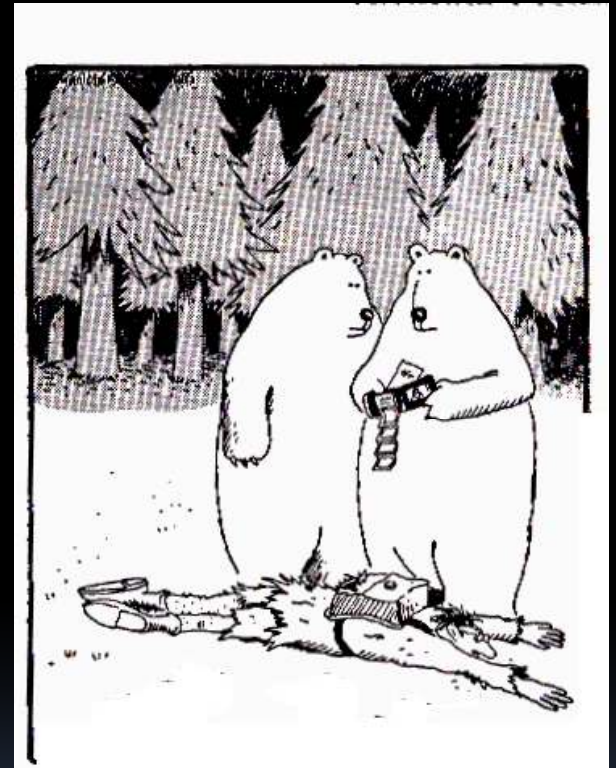
About Iowa...

- IA's developmental disability system serves about 15,339 people (ICF-MR & HCBS) at a total cost of about \$591 million.
- A little more than half the money (51%) is spent on community services. Nationally, 65% is spent on community services.
- IA serves a lot of people per 100k population (511 in IA vs. 203 nationally)
- A lot of people live in facilities of 7 or more (1,851 live in 16+ facilities).
- 10.6% of institution residents are under 21. Nationally, it totals 4.6%.
- About 37% receive services while living at home. (Nat'l average is 57%)
- IA doesn't spend much per person overall (\$38,575 in IA vs. \$55,433 nationally). HCBS spending is among the lowest per person (\$22,992), but spending on ICF-MR services per person (\$135,350) is above the national average.
- Relative to other states... IA spends a high percentage of its overall Medicaid funds on ICF-MR & HCBS services (21% in IA vs. 10% nationally)



Work Force Shortages Are Real

- Providers have trouble hiring and keeping staff.
- Families have trouble hiring respite workers.
- Pay is low. Benefits are not always the greatest.
- There are often issues to overcome related to culture and staff.
- We imagine systems that are well staffed by well trained people.
- We compensate with a mountain of rules, pre-scripted routines and paperwork.



*He's broke.
Must be a direct
support worker...*

Self-Advocates Say...

That Self-Determination
means that...

- I am a person like all people.
- I make my own choices.
- I am the boss of my own life.
- I make my decisions in my own life.
- I do for myself... and not depend on others so much.



When We Ask Self-Advocates...

(In New Hampshire, Alabama, Mississippi, Texas, Oregon, Colorado, North Carolina, Arizona, Idaho, Montana, Virginia, Missouri, Montana ...)



- What or who helps you to be in control of your life?

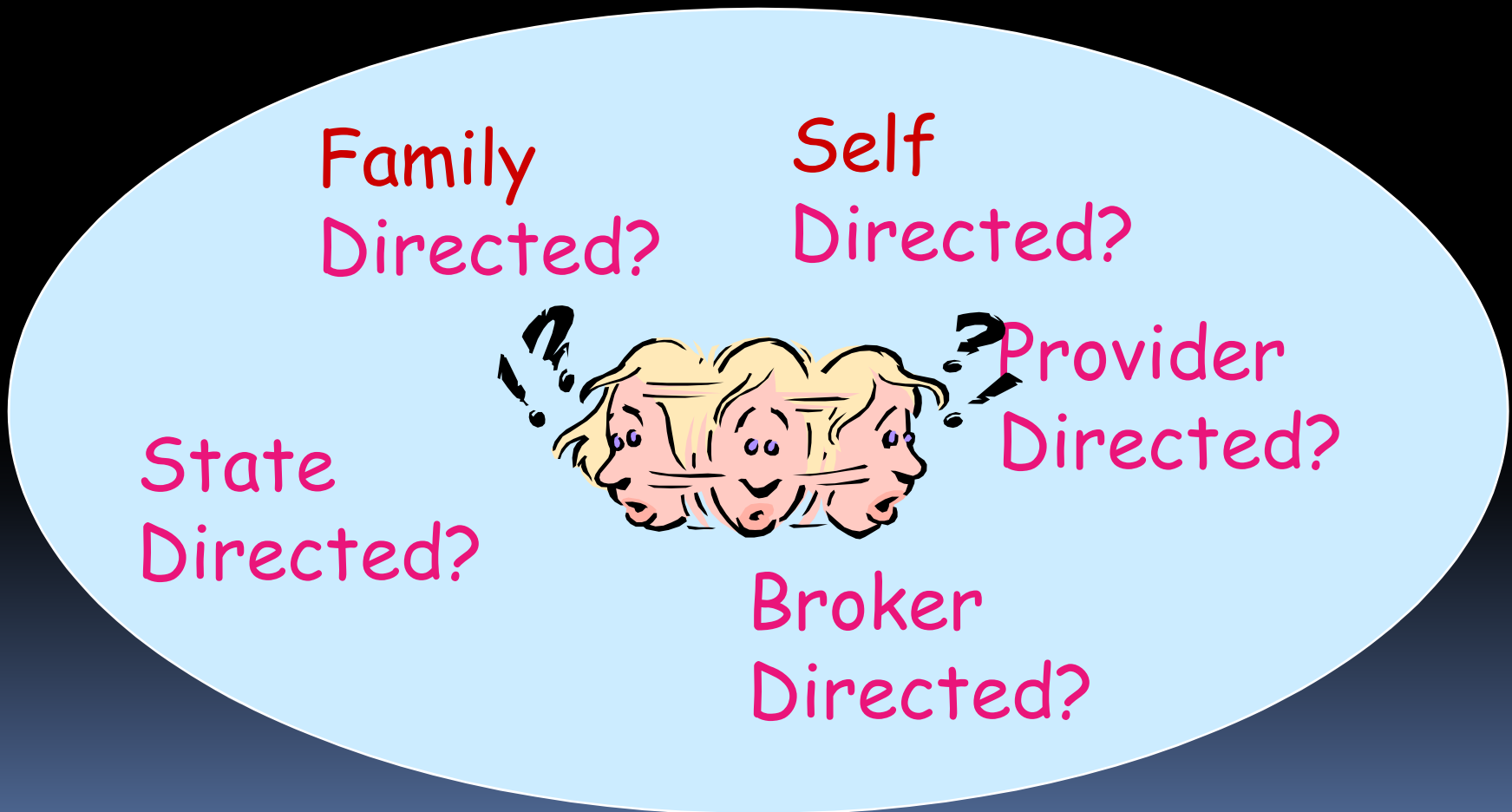
Very quickly someone will say... "My Parents." And many will agree.

- What or who keeps you from being in control of your life?

Very quickly someone will say... "My Parents." And many will agree.

Considering the “Rub”...

Who Is “The Self” In Self-Determination?



Heading for a crash!

**Weighty Legacy
Services & Structures**



**Rising
Demand**



**Workforce
Shortages**



Fragmentation



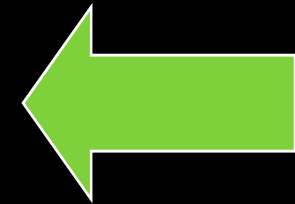
**Quality
Problems**



**Antiquated
Technologies**

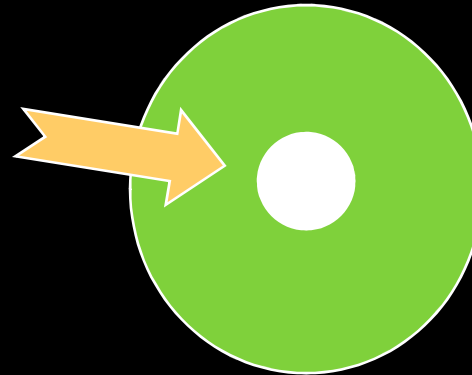


**Budget
Shortfalls**



What To Do???

We can't stay on
this spot



We need to rethink what
we do – affirm our
values but resolutely
search for “value”



Sustainable Futures ...

*An action agenda anchored in **values** and committed to making the **changes** necessary to secure the best **outcomes** possible for people with developmental disabilities and families.*

What We Can We Do To Develop a Sustainable Future for Family Support Systems

1. Hear self—advocates
2. Make our services systems efficient
3. **Rediscover ourselves and our communities.**



It can't ALL be about Medicaid!

1. Hear Self-Advocates

People want to live the life they want in the community with the support they need. Just like anyone else.



Issue 16

April 2008

The Riot!

Guardianship Issue!

A National E-Newsletter from the Self-Advocate Leadership Network @ HSRI

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SABE 2008 Conference

Indianapolis, IN

September 4-7

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Who's In Charge?

Self-Advocates Wonder About Guardianship

The word "guardianship" describes a relationship between people. It is a legal arrangement that is decided by a court. It gives a legal guardian the power to care for another person. This can include control over what that person does and over his or her property.



The court gives this power to a "guardian" when it thinks that the person, called a "ward," can not care for him or herself.



Parents seek guardianship of their adult sons and daughters. They worry that their family member will not be able to stay safe, manage their money, or make big life decisions on their own.

This is not always bad. For instance, in a hospital it can be good to have a guardian to make sure that a self-advocate gets the best care.

Yet, self-advocates say guardians are used when not needed. Or, they use their power to overrule the opinion of a self-advocate. Guardianship can put a big limit on a person's want to be in charge of their own life.

There are also alternatives to guardianship. Person-centered planning and services are a good start. Power in decision making can also be shared. Guardianship can also be limited to specific types of life situations.

Self-advocates think it's time to rethink guardianship.

Man Wins Millions!

Wins big and plays big too

Did you see the big news story? Rob Johnson of Idaho won the 2.5 million dollar lottery!



Rob lives with his parents and has cerebral palsy. When asked what he will do with his new fortune he said that he was moving to Hollywood and hiring the Dallas Cowboy Cheerleaders for his

support people.

After that, he said he will "buy out an amusement park for the day so I can ride all the rides."

Rob wasn't done yet! Next, he said he will "buy a fancy new lift van with a tub in the back to fill up with candy! Then I'll eat the biggest ice cream ever made!"

Rob was last seen with an ice cream cone in an amusement park with a Cowboy cheerleader. Good luck Rob!

April Fools!!



Contact us! Call 503-924-3783 x 30, or visit us on the web at www.theriotrocks.org

www.theriotrocks.org

It's Free... but contributions are most welcome

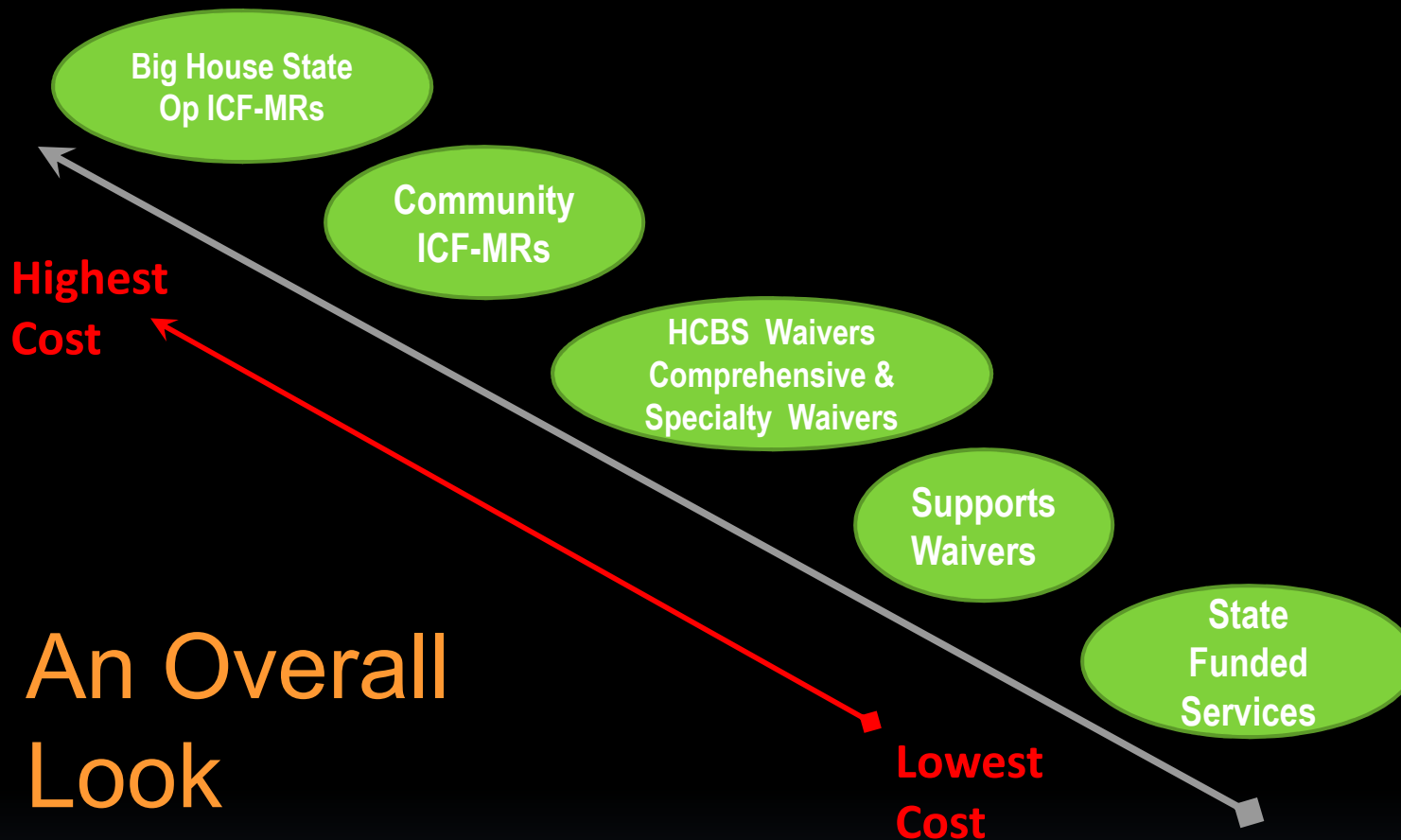
Human Services Research Institute

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2. Make Our Service Systems More Efficient

- Promote person-centered system architecture
- Encourage providers to be agile and utilize “Non-traditional” providers
- Disinvest from low value/high cost services
- **Rethink Medicaid!**
- Make systems fair and more efficient





An Overall Look at Things



3. Rediscover Ourselves and Our Communities

**A Three
Legged
Approach!**



Individuals

Community

Government



1st leg... Government

- A need to settle on a direction...
- A need for greater efficiency...





2nd leg... Community

- Enlisting community businesses
- Enlisting faith-based organizations
- Enlisting community serving organizations



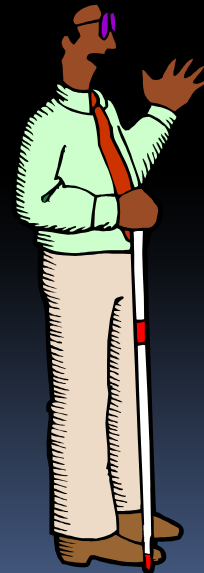
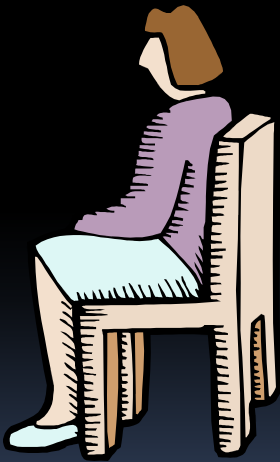




3rd leg...

People Helping People

Me + Me + Me = We



People Helping Others in the Community

- We want things from our communities
- Can we think of ways to contribute to the community?
 - Hospital Fun Runs
 - Blood drives
 - Park Clean Ups
 - Volunteering at shelters
- The Corporation for National Community Service?
 - Americorps
 - Learn & Serve America
 - Americorps/VISTA
 - Senior Corps

<http://www.nationalservice.gov/>

<http://www.serviceandinclusion.org/>



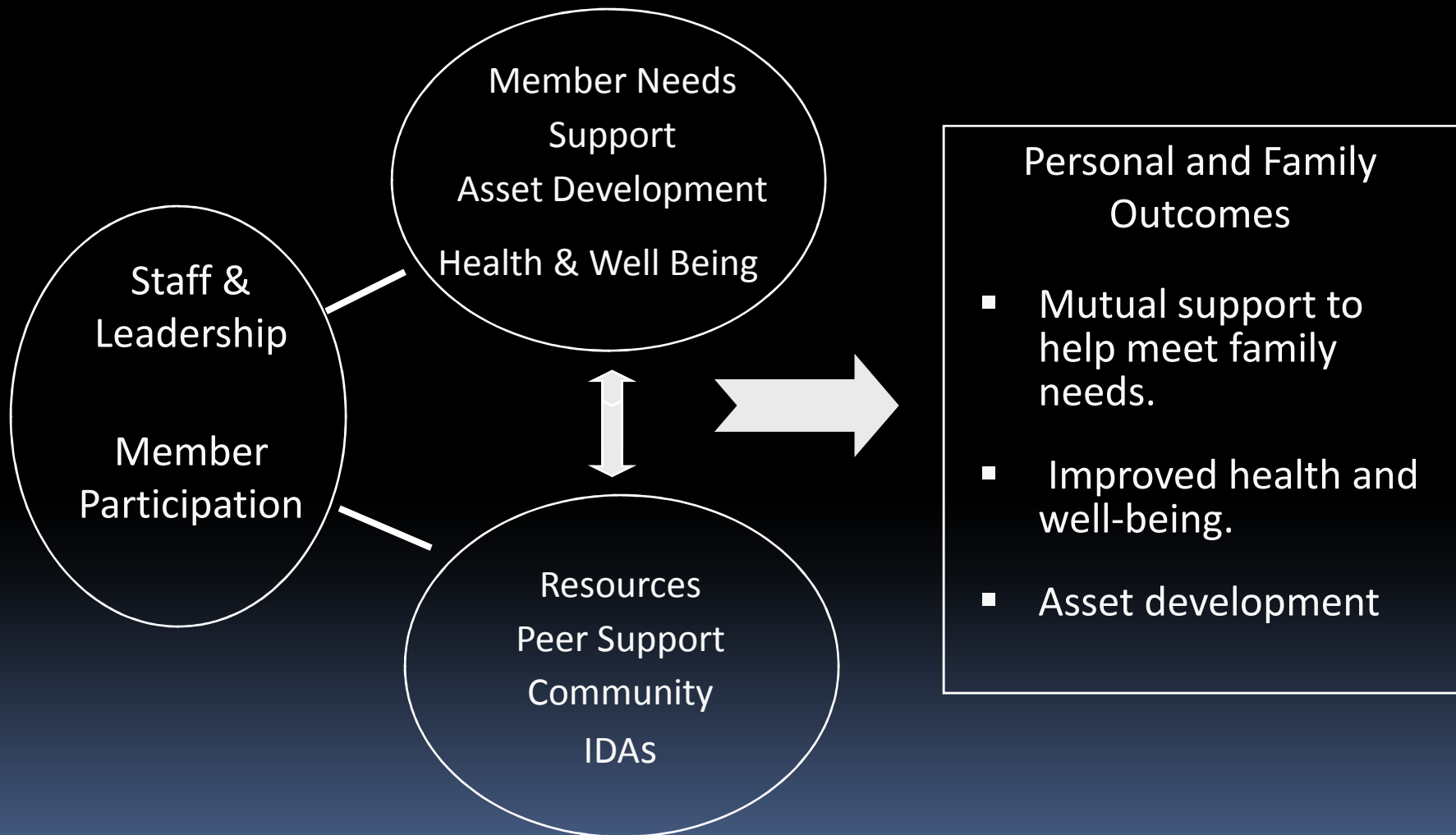
Yeah... So... What About...

Family and Peer Cooperatives?

In a cooperative participants unite to address common or individual needs through mutual support and/or joint action.



The General Approach...



In Wisconsin...

- Families and self-advocates are thinking through a cooperative concept
- Within their new managed care option (Family Care) individual may opt out and choose a “self-directed” option called IRIS.
- People are discovering how the waiver, coops and peer networks fit together



- HSC® Companies are recognized by the Federated Human Service Cooperative
- The goal is to “assist in the creation of Human Service Cooperatives and other self directed companies. (See <http://www.federatedhsc.coop/>)
- This entity develops and certifies local cooperatives directed by individuals and families who use disability services .
- Once certified, a cooperative operates as a provider .
- This type of cooperative is built on partnerships developed between agencies and community-service organizations in the public and private sector.
- These partnerships create a responsive network to offer self-directed services addressing member needs.



Federated Human Service Coops

- Several local HSC Companies have been successfully implemented

Arizona Autism United, (AZA United) Phoenix Arizona
<http://www.azaunited.org>

Arizona Service Co-op Enterprise, (ASCENT, HSC®), Flagstaff Arizona
<http://www.ascenthsc.org>

Inspire, HSC®, Phoenix, AZ, <http://inspirehsc.org>

Freedom Co-op, Memphis TN

Keep Marin Green Cooperative; San Rafael, California

Total Link 2 Community Cooperative, (Total Link 2); Northbrook Illinois

Community Choices Cooperative, Champaign, Illinois

An Added Twist...

Individual Development Accounts



Individual Development Accounts (IDAs) are matched savings accounts that enable low-income American families to save, build assets, and enter the financial mainstream.

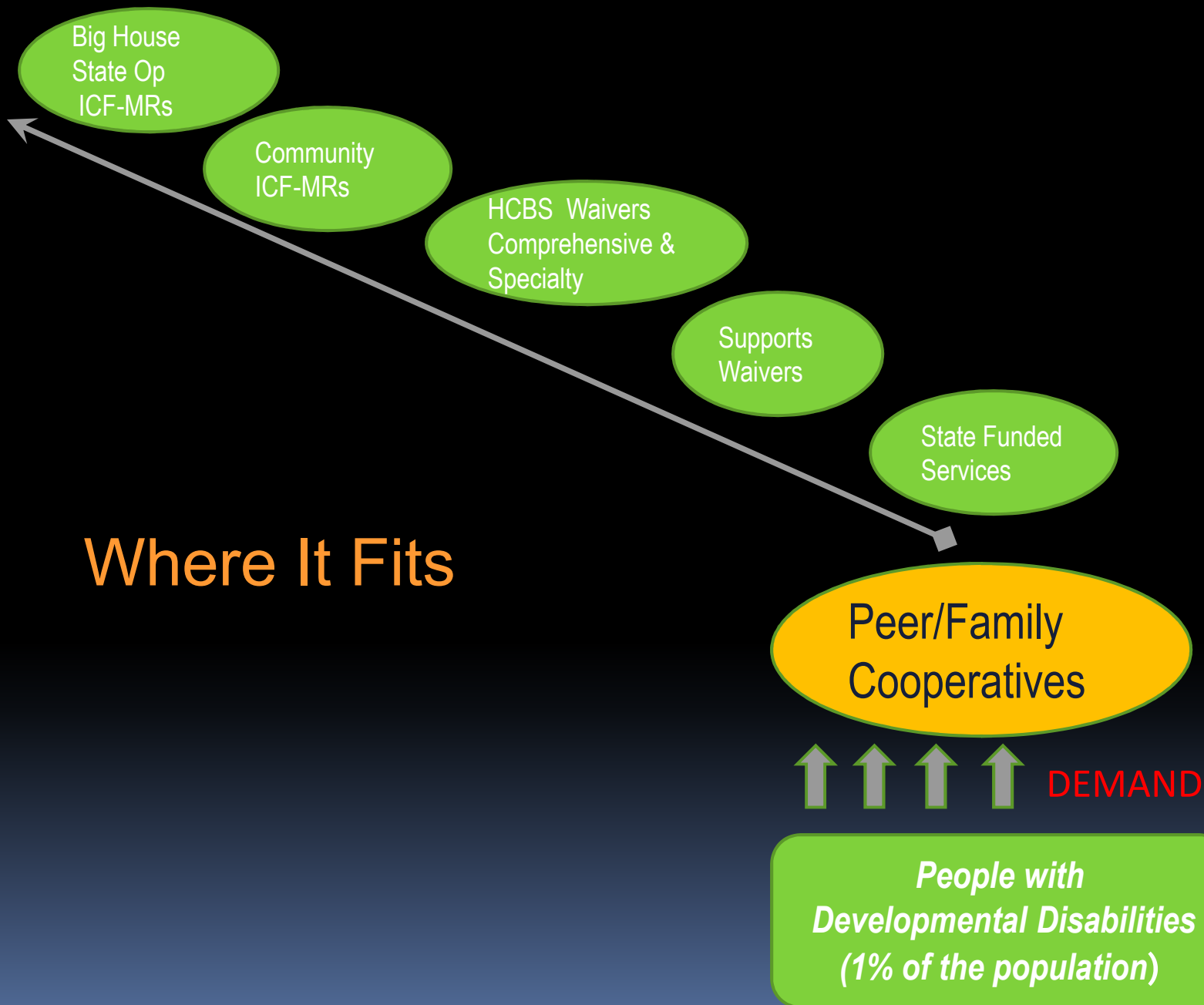
Key Concepts:

Low income Americans

Asset development

Matched savings accounts

<http://www.cfed.org/>



Where It Fits

The Way Things Are...

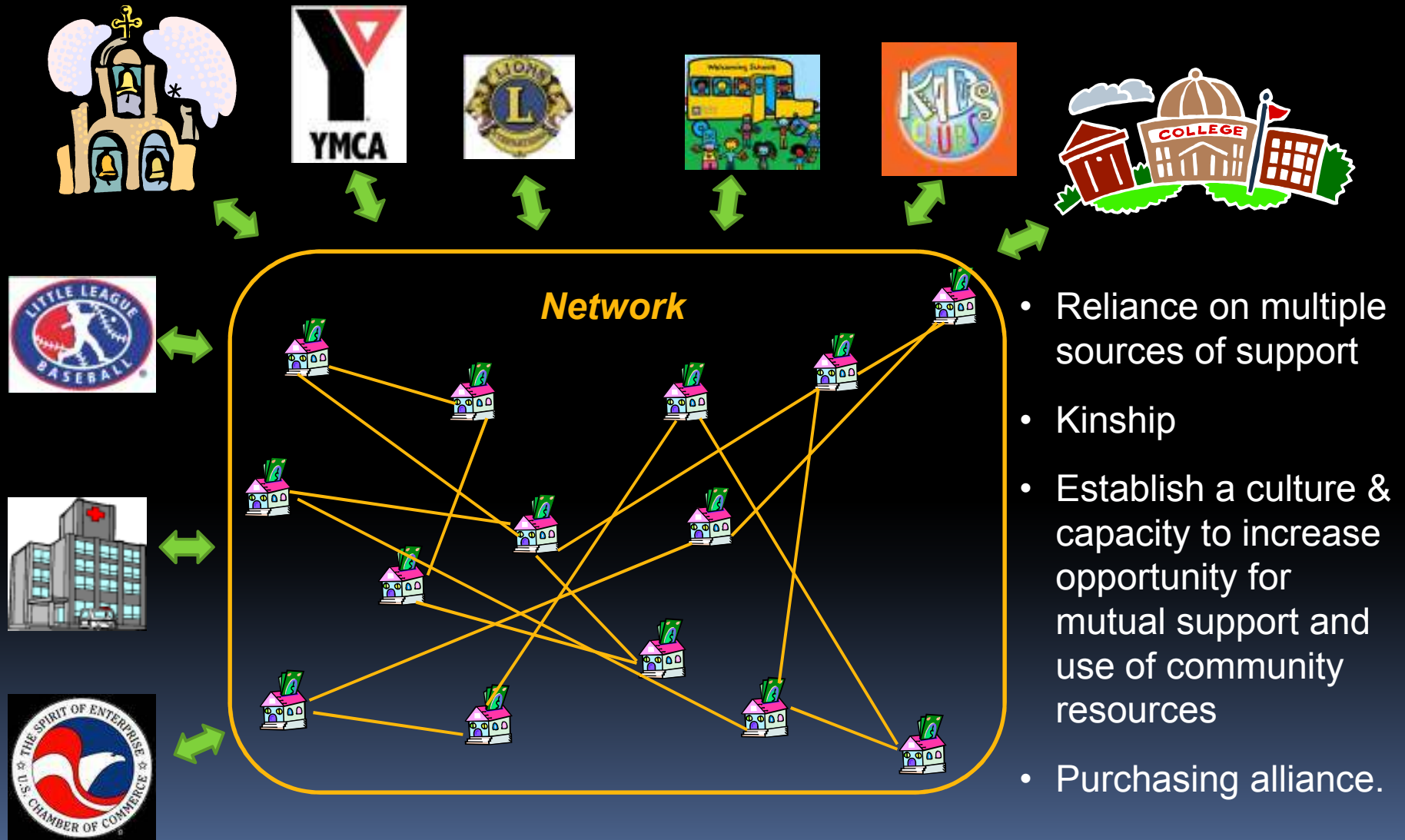
Medicaid Money is dropped into isolated households.



- Dependency on Medicaid
- Isolation
- Failure to build culture & capacity to increase opportunity for mutual support and use of community resources.

The Way Forward...

Medicaid works together with mutual support and use of community assets.



Family Support 360s...

21 Implementation Grants

Alaska
Colorado
District of Columbia
Hawaii
Idaho
Maryland
Massachusetts
Michigan
Minnesota
Missouri
New Hampshire
New Mexico
North Carolina
Northern Mariana Islands
Oklahoma
Oregon
Rhode Island
South Dakota
Utah
Vermont
Wisconsin

9 Planning Grants

Connecticut
Delaware
Illinois
Iowa
Mississippi
New Jersey
North Dakota
Ohio
Tennessee

- Funded by the US Administration on Developmental Disabilities since 2003
- Receive no state or Medicaid Funding
- Designed initially as “One Stop Centers”

www.addfamilysupport360.org



Family Support 360s...

- Develop staff as “family navigators,”
- Find that families and individuals often have support needs that fall outside of what traditional developmental disability systems address.
- Assist families to apply for and receive services from a variety of public service agencies,
- Utilize resources available outside the public service system, including faith-based and other community serving organizations, and businesses
- Develop effective opportunities for families to provide support to one another.



Family Support 360s...

Numbers of Families Served by Service Type (Unduplicated Counts)

(20 Of 21 Centers responding) (July 07 through July 08)

1,426 families	Comprehensive Assistance
2,766 families	Casual Assistance
1,915 families	Participated in Center Activities
5,499 families served	

At a cost of (based on a budget of \$4,140,000):

\$752/family overall

\$2,903/family (counting Comprehensive Assistance only)

What Are You Going To Do About It?

- What traditions, commitments and vision define us?
- What assets can we count on and leverage?
- What alliances can we forge?
- What opportunities will we create?

If I am only for myself,
who is for me?

And if I am only for
myself, what am I?

And if not now, when?

Rabbi Hillel



Next Generation of Family Support Systems

Next
Generation
of Family
Support
Service
Recipients

Policy
Challenges

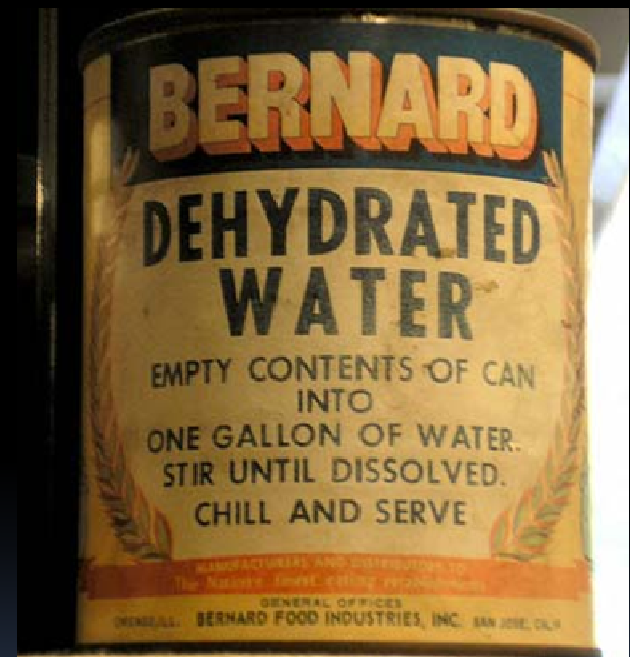
Next Generation Policies and Practices

- emphasis on considering the multiple facets of life
- emphasis on individual and family leadership
- emphasis on cultural competence
- emphasis on promoting systems efficiency
- emphasis on effective collaboration
- emphasis on effective use of community assets
- emphasis on fitting it all together to utilize and blend together multiple resources

**Valued
Outcomes**
for
individuals,
families and
systems

And So... In the End... We Must...

- Listen to what self-advocates are telling us.
- Make our service systems much more efficient. Let's stop throwing good money after bad.
- Rediscover the assets within ourselves and our communities

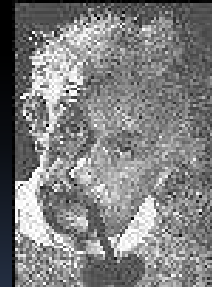


The Challenge Is To Find Ways To ...

- Encourage, model and support an “action bias” consistent with retooling...
- Encourage, nurture and support alliances that work to mobilize energy to act...

Anyone who has never made a mistake has never tried anything new.

Albert Einstein



The Fundamental Issues to Overcome Are:



- **Technical**

Can we figure out ways to make the structure work in a technical sense?

- **Political**

Do we have the will to make changes to the flow of money?

Can we abandon program (slot) driven approaches?

Can we move from supply centered to demand centered systems?

Concluding Thoughts

Let's Agree to Change.

- Change imposes choice.
- Choice imposes ambiguity.
- Ambiguity promotes discussion.
- Discussion promotes deliberation.
- Deliberation forms opinion.
- Opinion leads to action.



Need and Opportunity

A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."

Alfred Dam (undated)
Denmark

